

The Cancer Weapon

South Carolina Needs Most

Why do South Carolina men have higher death rates from prostate cancer than other U.S. men?

Why is brain cancer, a rare disease, among the top nine causes of cancer deaths among white people in S.C.?

Why do women in Bamberg County have the state's highest death rate from breast cancer?

Why do African-Americans in the Lowcountry have one of the nation's highest death rates from esophageal cancer?



South Carolina
Central Cancer Registry

SC Department of Health
& Environmental Control

We can't answer those questions because South Carolina is one of only nine states without a statewide central cancer registry. Most people today fear cancer more than any other disease. While we often see cancer as one illness, like measles, it's really more than 100 different diseases. In the sometimes baffling war against South Carolina's second leading cause of death, a central cancer registry can be a vital weapon.

What is a Central Cancer Registry?

A central registry collects statistics on all cancer patients in a state. The data system is designed especially to manage and analyze information about cancer cases. The basic information comes from patients' medical records. All names and data that could identify a patient are kept confidential.

For every patient, the registry will include:

- when the cancer was diagnosed
- where the cancer occurred in the body
- how far advanced the cancer was when it was found
- the specific type of cancer out of the more than 100 possible types
- the patient's treatment
- basics like age, race, gender and county of residence

A central cancer registry studies trends in how often cancers occur in a defined area, changes in diagnosis and treatments, and patients' survival rates.

How a Cancer Registry Can Help Save Lives

A registry would help explain why S.C. men with prostate cancer are more likely to die than other men in the U.S. It would also show why women in Bamberg County have the state's highest death rate from breast cancer. For example, a registry would show whether cancers were detected after they had spread in the patient's body. That would mean people were not being screened for cancer early enough, because they didn't know they needed it, or because screening wasn't available in their area.

A registry also lets doctors who treat cancer patients evaluate the success of cancer treatments. It gives hospitals information to evaluate the quality of their patient care. And it helps the American Cancer Society and other groups coordinate cancer control activities.

How a Registry Can Save Health Care Dollars

Treating just one advanced case of cervical cancer, for example, costs \$17,000 more than treating a case detected early. A complete central cancer registry could save these costs by pinpointing areas of the state where people were not getting early screening, and where education campaigns would be most effective in helping people reduce their risks of disease.

How a Registry Can Reassure Us

People in an upstate neighborhood thought there were more cases of cancer than normal in their area. They suspected that chemicals from a nearby factory were to blame. Their hospital reported data to the central registry, so DHEC's cancer investigators could use the data to study the problem. They found that the number of cancers was not higher than the number expected, and that no cancer-causing chemicals had been released from the plant.

Only about 10 per cent of suspected "outbreaks" in the United States have turned out to be true clusters of cancer cases. But they all need to be investigated thoroughly. The cancer investigators cannot know how many new cases occur in areas where the hospitals and doctors do not report to the central registry.

A complete central cancer registry could provide the information we need to decide if a group of cancers really does have a common cause and is a true cluster. If it is, then DHEC can take action to solve the problem that contributes to cancer. A registry also could help reassure most South Carolinians that their neighborhoods and work places are safe.

A South Carolina Registry for All South Carolinians

Several national groups keep statistics about cancer for about 30 percent of people in the U.S. But national registries can't help with local problems, like a suspected cancer cluster near an abandoned chemical plant.

The American Cancer Society also estimates the number of cases that might occur each year. But they cannot show the state's true number of new cancer cases each year. We need a statewide cancer registry for **all** cancer patients in South Carolina to get a complete picture of how people in our state are affected by the disease.

A Public-private Partnership

In June 1993, DHEC began collecting statistics only on breast and cervical cancer with funds from the Centers for Disease Control and Prevention (CDC). This pilot registry receives data from 46 of the state's 71 acute-care hospitals, either individually or through one of the state's three regional cancer registries. The registry is linked to health planning organizations through the Cancer Registry Steering Committee.

The Centers for Disease Control and Prevention awarded DHEC a grant to expand the pilot registry into a complete central registry to collect information on all new cancer cases in all South Carolinians. Data will be collected and reported according to international standards developed by the North American Association of Central Cancer Registries.

"People do not naturally rally round a cause like cancer record-keeping because no one can point to victims who will suffer without it. Rather it is our larger understanding of cancer that suffers. And thus, we are all victims."

John M. Healy, M.D.

*Memorial Sloan-Kettering
Cancer Center,
in Reader's Digest*



Confidentiality and Data Use

The right to privacy is a basic right of every South Carolinian. Protecting patients' privacy is a major goal of the S.C. Central Cancer Registry. All data showing patients' identity will be restricted. The Registry will not release data showing a patient's identity unless a mandate has been established by statutory law.

A data use committee will review all requests for data. Doctors and health care researchers will be able to use the data, as long as patients' privacy is protected and the researchers follow the committee's rules. The SCCCR believes that its data should be understandable to the general public and to government agencies.

What You Can Do About Cancer

We sometimes feel powerless over diseases as dreaded as cancer. But all of us can do something.

Everyone:

- Have regular screening for cancer according to ACS guidelines.
- If you have cancer, urge your doctor to report the information to the S.C. Central Cancer Registry.

Health professionals:

- Provide information on new cancer patients to the S.C. Central Cancer Registry.
- Encourage your colleagues to report also.
- Make sure the hospitals where you practice report their cancer data.
- Offer cancer screening or refer your patients according to American Cancer Society guidelines.

For more information

S.C. Central Cancer Registry: (803) 734-4683
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Designed by the Division of Media Services
for the Center for Health Promotion
Division of Cancer Prevention and Control
& the Office of Vital Records and Public Health Statistics
2A-1035 4/95



SC Department of Health
& Environmental Control